



DENNIS COOK/AP

**CHILDREN'S CONGRESS:**

Actors Kevin Kline and Mary Tyler Moore and astronaut James Lovell called for increased funding for diabetes research at a Senate hearing.

**THE LAYPEOPLE WHO RUN THE JUVENILE DIABETES RESEARCH FOUNDATION HAVE MASTERED FUNDRAISING AND PUBLIC ADVOCACY — BUT NOT THE CLOSED-DOOR POLITICS OF THE SCIENCE COMMUNITY.**

BY NEIL MUNRO ■

# Charitable Choices

**I**n 2001, Denise Faustman, an associate professor at Harvard Medical School and the director of the immunobiology lab at Massachusetts General Hospital, announced a surprising laboratory discovery in her research on diabetes.

Faustman had injected a compound called BCG into diabetic mice, expecting that it would help repair their haywire immune systems. Diabetes occurs

when the immune system goes awry and gradually destroys the insulin-producing islet cells in the pancreas. The BCG injection worked as Faustman had expected. But upon dissecting the animals, she also found that, in most of the mice, the pancreas was restored to health.

Faustman reported her news-making results in a top-tier publication, *The Journal of Clinical Investigation*. In 2003, she published an update in the magazine *Science*, describing evidence that in mice, stem cells migrated from their spleens and repaired their pancreases. Faustman next won the backing of some top diabetes researchers; boosted the cure rate in

diabetic mice; got approval from the Food and Drug Administration for limited testing of BCG on people; and applied for grants to further her research.

She also got three rejection notices in the mail from the Juvenile Diabetes Research Foundation. "We don't fund work that does not meet the standards of our lay and peer reviewers," Peter Van Etten, president and CEO of the JDRF, told *National Journal*. "The fact that this [proposed treatment] is popular, and there is great support for it, is not justification to violate the policies we have established over many years."

As the world's leading charitable fundraiser and advocate

for research on juvenile diabetes, the New York City-based JDRF doled out \$93 million in 2004 to help researchers find a cure for a disease that afflicts 1.3 million American children. An accomplished researcher like Faustman would seem to be an ideal candidate to receive some of that financial support.

But there is a complicated back story to the rejection letters that Faustman received from the foundation—a story that involves scientists' collective and individual ambitions; political disputes over stem-cell research; \$3 billion in California taxpayer money; and the balance of power within the JDRF between the science professionals on the one hand and, on the other, the lay members whose children suffer from diabetes.

As is true elsewhere in the medical-research community, JDRF's grant-making process fosters furious competition among research advocates for money. JDRF board member Margery Perry, a nonscientist and the chair of the research committee, calls the process "a mirror of human nature. You see some scientists that are extremely collaborative and very sharing, and you see the exact opposite."

#### THE FACE OF A CHILD

By Washington standards, the JDRF is a highly successful operation. The organization began with only a few parents when it was launched in 1970, and now boasts thousands of volunteers in 100 locations worldwide. The 39-person board of directors and several advisory committees oversee the sophisticated lobbying efforts and fundraising programs that allowed the JDRF in fiscal 2003 to award 500 grants to researchers in 19 countries, and put \$30 million into communications and education efforts. Most of that research funding went to university-affiliated scientists in the United States; a remarkably low 10 percent was spent on operating costs and fundraising expenses.

And the JDRF gets high marks for visibility. Actress Mary Tyler Moore is the group's international chairman, and other celebrities have also helped with fundraising and raising public awareness of juvenile diabetes.

Juvenile, or Type 1, diabetes is a gene-related disease in which the immune system attacks the insulin-producing cells in the pancreas. Without a well-regulated supply of insulin, other organs begin to fail, eventually causing blindness, kidney failure, and death. Although there's no cure, many scientists, as well as pharmaceutical, biotech, and medical companies, have developed knowledge and products that help patients regulate or slow the disease through a regimen of diet, exercise, pills, insulin injections, and blood-sugar monitoring. Adult, or Type 2, diabetes, which afflicts some 16 million Americans, manifests later in life and is often related to poor diet and obesity. The direct financial cost of all diabetes care in the United States was \$92 billion in 2002, according to a study by the Lewin Group.

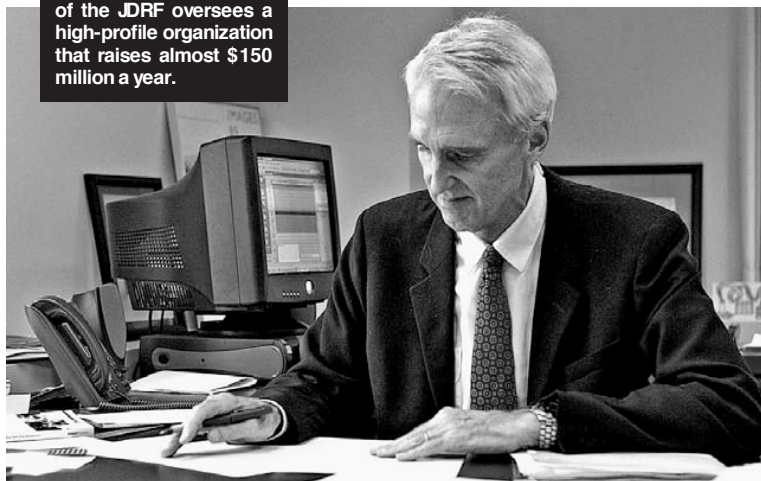
One of the JDRF's most visible weapons in the fight against juvenile diabetes is the afflicted children. They're young and often outwardly healthy. Many of their parents are educated and wealthy, and they know how to attract

media attention, solicit donations, and build political influence. "You would be hard-pressed to look into the face of a child—as legislators do—and tell them you do not support their hope for a cure for diabetes," said JDRF spokesman Peter Cleary. The JDRF organizes a "Children's Congress" and a "Promise to Remember Me" campaign, in which kids and their families visit Capitol Hill lawmakers. These visits have been "enormously successful," said JDRF board member Maureen Barunas, whose teenage son lobbied Congress in 2001. "The point is to bring their personal stories, to put a face on the story of diabetes."

In recent years, the JDRF, which employs three staff lobbyists in Washington, has helped persuade Congress to give the scientists at the National Institutes of Health an additional \$750 million over five years for investigating juvenile diabetes. And JDRF's adult volunteers are now raising almost \$150 million per year in charitable donations; in 2004, JDRF's executives set a higher fundraising goal of \$200 million a year. More-

#### PETER VAN ETTEN:

The president and CEO of the JDRF oversees a high-profile organization that raises almost \$150 million a year.



over, Congress passed a law in 2004 intended to promote Medicare funding for a new form of diabetes therapy—the Edmonton Protocol—that several medical centers around the country now provide.

The JDRF also works with other Washington-based advocacy organizations. In the campaign for embryo-stem-cell research, for example, the foundation has played the leading role alongside scientists, universities, and biotech companies that try to persuade others of their belief that embryo stem cells can be used to understand the workings of the human body. Rep. Michael Castle, R-Del., a supporter of embryo-stem-cell research, told *National Journal* that the effort is "the best lobbying campaign I've ever seen." The scientists rallied by the JDRF are particularly influential: "Their words are my words," said Castle.

So far, the broad campaign has persuaded President Bush—despite strong opposition from his social-conservative base—to allow federal funding for a limited kind of embryo research; has won over a slew of legislators who have impeccable anti-abortion credentials; and has gained near-uniform backing from Democrats and socially liberal Republicans. The push for embryo research has generated a wave of media coverage, and in November it helped pass a California ballot

The push for embryo research has generated a wave of media coverage, and in November it helped pass a California ballot initiative that will pump \$3 billion into the state's universities and biotech centers for stem-cell research.

For all its lobbying and fundraising successes, however, the JDRF can claim few clear achievements in curing or even treating juvenile diabetes. In interviews for this article, JDRF officials repeatedly pointed to their support of the recently developed Edmonton Protocol, in which pancreas cells from cadavers are transplanted into patients with a severe form of diabetes. But the protocol's co-developer, James Shapiro, a researcher at the University of Alberta in Canada, said that the JDRF had played no direct role in its development. The protocol, moreover, is of modest benefit because of several problems: Not many cadaver cells are available; the operation is very expensive; the patients suffer debilitating side effects from anti-rejection drugs; and after a few years, the transplanted cells die. About 300 patients have received the treatment so far.

Former top Time Warner executive J. Richard Munro (no relation to the author) chaired the JDRF board in 1992 and 1993 but is no longer involved with the foundation. For 25 years, ever since his two sons became diabetic, he complains, JDRF people "have said, 'We're making real progress,' and my answer is, B.S. There's nothing that's changed for my sons since they became diabetic."

Still, in science, lack of success is not conclusive evidence of failure. Diabetes is a difficult disease, and lots of funding, much trial-and-error, the generous use of partial therapies, many disappointments, and periodic false hopes are to be expected before a cure appears. Even when a major therapy is first developed, there's likely to be much professional disagreement before the therapy has proved effective on many patients. That reality gives JDRF's nonscientist lay leaders the difficult task of navigating a path guided by advice from competing advocates.

Lay members repeatedly say that their goal is a cure—not the scientific knowledge sought by university-affiliated scientists, and not the revenues sought by companies selling products that ameliorate the effects of diabetes. This goal, however, cannot be accomplished by JDRF's laypeople alone, because they are dependent on the corps of diabetes scientists.

When a new scientific claim is raised, "we can only vet it by asking other independent scientists [and] our staff, who don't have biases," said JDRF board member Roy Smith, a former international banker at Goldman Sachs and a finance professor at New York University who headed the JDRF planning committee in 2002. Said former board member Munro: "There's no way that I could second-guess a scientist—it would be foolhardy.... 'Blind faith' is an awful thing to say, but that's pretty much how I thought [JDRF's grant-giving] worked. You hoped it was being spread to the right people, but there was no way you could be sure."

#### BALANCING ACT

When it comes to their professional culture and economy, diabetes scientists are no different from other scientists: They are simultaneously allies and rivals. They compete for pres-

tige and for the resources that generate prestige—grants, publishing opportunities, and patents—even as they cooperate to lobby for greater federal funding and for freedom from federal regulation.

Professional and personal rivalries among researchers can be intense, but are also moderated by their shared dependence on each other for funding, which is typically awarded by peer-review panels of fellow scientists. Diane Mathis, a researcher at Harvard's Joslin Diabetes Center whose work is funded partly by the JDRF, said, "We do depend [on each other], but we like to think ... [that] we're judged objectively on the science, not on whether our colleagues like us or not."

Within this community, scientists hold overlapping affiliations with rival universities, companies, cliques, specialties, and preferences. These splits create conflicts, as well as a confluence of interests. To prosper in this professional economy, scientists need a keen eye for peer politics, business, and science. "I think I learned not too long ago that scientists are just about as political as any other group. They have their own agendas," Munro said.

Faustman is no exception. In her work at Massachusetts General Hospital and at Harvard Medical School, she has written or contributed to more than 100 published papers, has reviewed grant requests for the JDRF, and chairs the board of the Society for Women's Health Research. In 1989, she helped form a company that was sold in 2003 for \$40 million. Also in 2003, she helped create Keel Pharmaceuticals, to commercialize her diabetes-related technology. Faustman promotes her work to the parents of diabetic children and the media.

The parents and lay members of JDRF, however, have a much narrower focus than the scientists do. "We have one agenda," Perry said. "We want a cure now for our kids and loved ones."

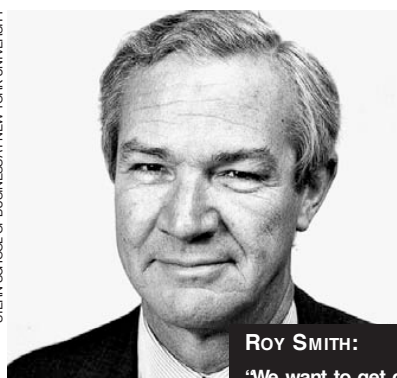
Balancing scientists' multiple priorities with lay members' single-minded goal of

finding a cure would be a challenge for any organization dedicated to fighting a disease. "All you can do is to try to minimize all those things that creep in," said Moira Murphy, a science adviser to Diabetes UK, a British patient-advocacy group akin to the JDRF. "You can never get rid of them."

The JDRF seems well prepared to manage such a challenge. "In every step of the process, we have an awful lot of committed volunteers that are connected to the disease and have no axes to grind, other than funding the best research possible," said lawyer Robert German, the father of a diabetic son and the chairman of the JDRF board. "I would not tolerate anything going on, other than what's contributing to a cure."

Far more than nearly all other disease-advocacy groups, the JDRF board and its committees are steered by laypeople, including top executives, lawyers, and other professionals, plus some executives from the health care sector. Many of these lay members have educated themselves about diabetes through their own work at the JDRF or through outside study, and this knowledge puts them in a position to spar with scientists over various issues. JDRF panels of laypeople

STERN SCHOOL OF BUSINESS AT NEW YORK UNIVERSITY



ROY SMITH:

"We want to get close to the clinical-trials phase.... We are tired of doing it to mice. We want to do it to humans."



review grant requests from scientists after panels of other scientists have ranked them in quality.

All laypeople and scientists must disclose possible conflicts of interest, and must remove themselves from any decision that could affect their personal interests, Van Etten said. For example, at the JDRF's twice-yearly review sessions, perhaps as many as 20 scientists exclude themselves from reviews of particular grants because they have a potential conflict of interest, according to Van Etten. Such potential conflicts are to be expected, he said, because the JDRF seeks out expertise wherever it can be found. "There is self-policing that takes place by the scientists."

Sometimes, the lay review committee does override the scientists' funding recommendations, according to Van Etten, who said he could not offer specific examples because of the desire to protect the confidentiality of the process. Perry, however, offered one example from a decade ago, in which lay members backed a proposal calling for the nation's small supply of insulin-producing cadaver cells to be shared by a wide range of researchers. The scientists on the peer-review panel had given the proposal a very low rating, but the project is now established, she said.

Laypeople and scientists also differ on policy priorities. Board member Smith said that the organization is "moving away" from university-based research efforts because "we want to get close to the clinical-trials phase of this stuff. We are tired of doing it to mice. We want to do it to humans." Board members also say that the JDRF needs to cast a wider net than the scientists' conventional wisdom. "We need to look beyond what people are telling us is possible and take some risk," Barunas said.

But, according to a recent article in *Forbes* that praised the JDRF, the foundation's policy is to "achieve more by moving toward fewer but bigger fixed-term collaborations with brand-name research institutions like Columbia and Harvard." JDRF spokesman Cleary said that the foundation began to develop such relationships several years ago, "and they continue to expand today."

To minimize conflicts of interest among board members, JDRF's directors also disclose their various interests. For example, the agenda-setting portfolio committee is chaired by Leo Mullin, the father of a diabetic child. Mullin, the former head of Delta Airlines, is on the board of pharmaceutical company Johnson & Johnson. Another JDRF board member, Charles J. Queenan III, is the No. 2 executive at Amaranth Bio, a diabetes-research firm. He joined the firm last year after serving as the chair of the JDRF research committee, a role filled by Perry since 2004.

#### THE FAUSTMAN CHALLENGE

Diane Faustman's requests for funding from 2002 to 2004 traveled through the JDRF's standard process, Van Etten said. But, he said, the foundation must keep its reasons for the rejection confidential, to protect its peer-review process from politicized pressure from grant seekers.

Faustman declined to provide copies of the JDRF's lengthy rejection notices, but she did release a copy of the foundation's June 2004 cover letter, which denied her request "based both on the scientific, peer-review assessment" of the



**DENISE FAUSTMAN:**

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medical science review committee and on the work of the lay review committee.

Faustman has her own explanation for the rejections. Science is "the only major industry where you have competitors reviewing competitors," she said. It's as if, when "you wanted to open a Krispy Kreme store, you had to get approval from Dunkin' Donuts," Faustman added, so "you'd have a lot of average doughnut shops." In particular, she said, the small community of diabetes researchers is "pretty inbred, and it results in mediocrity."

According to Faustman, the novelty of her organ-regeneration work is unnerving to other researchers. "Four years ago, nobody believed that adult organs [could] regrow," she said, calling her results "a major paradigm shift." This discovery, she argued, affects other scientists' research and business plans, especially those who are racing to create vats of embryo stem cells for transplantation into diabetes patients.

If Faustman's work is proved valid, it could lead to a cure for juvenile diabetes at modest cost, generating incalculable benefits for millions of people around the world. It could greatly lower the demand and the revenue for other therapies, such as the Edmonton Protocol, or for diabetes-related amelioration and maintenance products. The technique could also cut revenues for pharmaceutical companies, which take in roughly \$1.3 billion a year in the United States from the sale of insulin-related products. Much of the revenue from the new treatment would likely go to Faustman's own company, although hospitals and doctors would make some money from her treatment.

And such a breakthrough would likely affect funding for rival researchers in the \$500 million-a-year diabetes-research

COURTESY OF JACCOCA FOUNDATION

sector, including those active in the JDRF. They would likely see cuts in their research funding, and would perhaps migrate into new areas, where they would face uphill competition from researchers already established in those disciplines. This shift would be painful, partly because scientists are understandably reluctant to discard years of work and hopes. "If you have a belief, you pursue it, until it becomes totally and completely, undeniably wrong," said Joel Haben-er, a JDRF-funded researcher at Harvard Medical School.

Faustman's therapy could also have implications for research beyond diabetes, because it seemingly works by allowing the body to use its own stem cells to repair damaged organs once the disease is blocked. Numerous other autoimmune diseases—multiple sclerosis, lupus erythematosus, Lou Gehrig's disease (or ALS), muscular dystrophy—might also be treated in the same fashion, said Larry Raff, president of the Newton, Mass.-based Autoimmune Disease Research Foundation, which supports Faustman's approach.

Her approach clashes with that of advocates of embryo-stem-cell research, who already face opposition from a political coalition maintaining that adults' stem cells are a faster and more ethical alternative to embryo stem cells. Proponents of embryo-stem-cell research frequently cite diabetes—and diabetic children—as a primary reason for using embryo stem cells. But backers of adult stem cells note that Faustman's research could make that political argument moot if an adult's own stem cells can indeed repair diseased organs.

This political dispute is important to universities and biotech companies—and their backers in the pharmaceutical industry—who want to use stem cells, especially those from cloned and cultivated embryos, to cut the cost of discovering new drug formulas and to accelerate the testing of potential products.

The JDRF is a leading advocacy group in this larger stem-cell debate. In 2001, its senior lobbyist, Lawrence Soler, a diabetic, chaired the main embryo-cell-advocacy coalition, the Coalition for the Advancement of Medical Research. The coalition's board includes several research centers—Harvard, Columbia University, the University of Wisconsin (Madison), the University of California system—plus scientist-advocacy groups, the biotech industry, and several patient-advocacy groups. In 2004, the JDRF donated \$1 million to support the pro-stem-cell research initiative that passed in California.

Faustman's work threatens progress toward easier use of human embryos, said Raff. "If you can cure and treat diseases without embryo stem cells, through adult stem cells and their

permutations, then that entire other [embryo] side of the [medical] industry will have more difficulty raising venture-capital money and philanthropy."

Other researchers have reported breakthroughs using adult stem cells. Since 1997, researchers in Israel have been injecting BCG, the compound Faustman uses, into a person who was expected to develop diabetes. That patient has remained free of diabetes for seven years, said Naim Shehadeh, head of the pediatric diabetes clinic at the Technion Israel Institute of Technology. But researchers have been unable to gain additional funding for tests on more people. In Los Angeles, surgeon Michel Levesque, the chief of neurosurgery at Cedars Sinai Medical Center, used one patient's

stem cells in 1999 to nearly eliminate his symptoms of Parkinson's disease, but has since failed to win financial backing for a formal clinical trial of the therapy. Norman Ende, at the University of Medicine and Dentistry of New Jersey, says he has successfully treated diabetic mice with stem cells from umbilical cords, but has yet to win any support even in his university—not even permission to issue a press release.

In Faustman's case, her claim of ill treatment is impossible to verify. But there's much evidence that the JDRF has done little to aid or advertise her line of work, despite the lay members' promise to pursue any possible cure.

#### THE REVIEWERS

Although Van Etten declined to name the 20 scientists who reviewed Faustman's recent funding request, he said that board member Margery Perry and scientist

Mark Atkinson of the University of Florida and the chair of the JDRF science review committee selected the reviewers.

Like Faustman, Atkinson is a major figure in diabetes. His 2002 résumé runs to 25 pages and describes his then-current work on 11 grants valued at \$23.7 million; his five patents; the 108 scientific articles that he wrote or contributed to; and the two companies for which he had worked as a science adviser. He also plays a prominent role in the Immune Tolerance Network, a project funded with \$113 million from NIH and \$14 million from the JDRF intended to test and approve the Edmonton Protocol. Atkinson's focus is genetic therapy, not the regeneration therapy Faustman is pushing.

Genetic engineering, which was widely touted in the 1980s, has fallen out of favor in recent years. For example, JDRF's funding for gene therapy has declined from \$15 million in 1999 to less than \$4 million in 2004. "We're seeing more opportunity in regeneration and islet transplantation,"



DON FRAZIER/SOUTHEAST MISSOURIAN

#### STILL NO CURE:

**A 12-year-old—one of the 1.3 million American children with diabetes—injects herself with insulin.**

Van Etten said. But Atkinson remains optimistic about his work. In each new field, he said, "the expectations get very high, very quick, and expectations don't often match up with reality." After additional research, he added, "'Bang!' It comes back. That's where I think gene therapy is right now."

Faustman's work, Atkinson said, is "pretty promising [and] could be huge." However, it is "very high-risk, high-reward [technology] that one has to approach with the highest degree of skepticism."

Board member Perry says much the same about Faustman's work, calling it "a very, very hot topic, so we need to get some people out there to figure out if this is real. I want her to be right, [because] I'll do anything for a cure." Nevertheless, Perry has not met with Faustman. "I just haven't had the opportunity," Perry said. "I'm on the road all the time."

Perry, a long-standing lay member of the JDRF, has a daughter who was diagnosed with diabetes at age 7. As chair of the research committee, Perry plays a gatekeeper role for the board; her committee does not give opinions on research but oversees the grant-review process. Said board member Aubrey Baillie: "If there are any significant disagreements [about scientific alternatives], those come through the director of research to the board." Board member German also defers to Perry: "I will trust Margery Perry with making sure the researchers' claims have been appropriately challenged."

Although JDRF's reviewers and lay members refused to support Faustman's research, they did fund three other researchers to test Faustman's claim: Emil Unanue, a prizewinning immunology scientist from the Washington University School of Medicine, St. Louis; Anita Chong, an associate professor at the University of Chicago; and Mathis from Harvard's Joslin Diabetes Center.

Chong, a young researcher specializing in transplants, said she won't be able to report her investigation of Faustman's alternative approach for another year, partly because the scientific-publishing process is slow. Unanue could not be reached for comment.

Mathis, an immune specialist, was skeptical about Faustman's work, saying that other studies showed an increase in diabetes when patients were injected with one of Faustman's compounds. "I would not want my kids to get treated on the basis of one experiment by one person," Mathis said. She also criticized Faustman for promoting her work, arguing that Faustman had created a "cult following." According to Mathis, scientists "at the JDRF have a much more scientific view of things than the parents."

Faustman's research is part of a larger trend in medicine, in which clinical researchers—usually in hospitals, rather than universities—are increasingly using patients' own stem cells to try to treat afflictions. At the same time, adult-stem-cell work has generated a strong reaction from scientists working with embryo stem cells, and has spurred publication of several medical journal articles attacking claims made by adult-cell researchers such as Faustman.

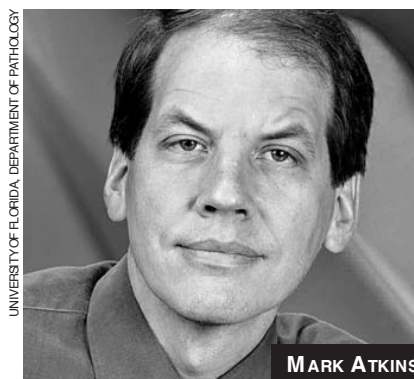
Embryo-cell advocates say that their research has two main benefits. First, it will provide basic scientific knowledge about how the body works. Second, they say they hope to cure dis-

eases, such as diabetes, by transplanting cells from the patients' clones back into the patients. To treat diabetes, advocates say, they hope to grow vats of cells for mass transplants into the patients.

But any success is still far off. "No one in human embryonic-stem cells will tell you that therapies are around the corner," said a spokeswoman for the Howard Hughes Medical Institute. The caution is widely shared. "Two years ago, [the embryonic-stem-cell field] was hype, hype, hype," said Atkinson, the gene-therapy advocate. "It is still that way in California, but I think that field has hit a bit of a wall," he told *National Journal*.

When asked about this adult-cell-versus-embryo-cell dispute, Van Etten acknowledged the surprising advances made by the adult-stem-cell faction. "There have been more promising results in adult stem cells than there have been in embryonic-stem cells ... [while] the principal benefit of [embryo-] stem-cell research is understanding nature," rather than transplant therapies, Van Etten said. By mid-2005, he predicted, the JDRF would be spending more on adult-cell research than on embryo-cell research.

But JDRF spokesman Cleary subsequently said in interview that in 2005, JDRF will spend roughly \$10 million on human embryo-stem-cell research, and \$4 million on adult-stem-cell research.



UNIVERSITY OF FLORIDA DEPARTMENT OF PATHOLOGY

**MARK ATKINSON:**  
Expectations in science research can "get very high, very quick, and expectations don't often match up with reality."

#### THE WORKSHOP

Partly because of Faustman's progress, many patients and scientists have called for additional work on adults' cells. "The respect for Dr. Faustman was such that we pulled together a workshop for scientists" to discuss regenerative therapies, said board member Gail Pressberg.

The March 2004 meeting of roughly 25 researchers, however, was called to discuss regeneration, not Faustman's work, said Richard Insel, JDRF's science director. Faustman did not deliver a presentation. The invited co-chairs of the meeting were Harvard researcher Doug Melton and Matthias von

Herrath, a diabetes researcher at the California-based La Jolla Institute for Allergy and Immunology, which is seeking to develop new drugs for biotech companies.

"There have been slightly excessive amounts of marketing for that particular therapeutic approach," von Herrath said in an interview, referring to Faustman's work. Von Herrath is trying to develop a vaccine-type treatment for children expected to get diabetes.

Melton, who has two children with diabetes, is a leading diabetes researcher at Harvard's Joslin Center, where his focus is on embryo stem cells. He recently asked his Harvard peers for approval to clone human embryos to get more stem cells desired for a variety of projects, according to an article in *The Washington Post*. Melton, who is seeking to raise \$100 million for his embryo-cell enterprise, gets critical funding from the Howard Hughes Institute and has strong political support for his work from other researchers, universities, and the JDRF.

Melton is also a businessman and a board member of Curis, a company that is trying to develop drugs for cancer,



baldness, and other ailments. He is publicly dismissive of the people—such as Faustman—who argue that diabetes can be treated with adults' stem cells. Such research is "a waste of precious time and effort," he told *The Wall Street Journal* last year. Asked about his various interests, Melton replied, in an e-mail to *National Journal*, "Multiple roles' are generally disclosed and are well known to the JDRF and to the audience."

The various difficulties in his research, and his own multiple roles, have not abated Melton's support at the JDRF. "I have the utmost respect for him," said James Lurie, the board's finance chairman. "We adore him," said board member Smith. Despite this lavish praise, the lay members' support for embryo research is not unlimited. "It could be that we have developed an institutional bias in favor of embryonic material," Smith said.

After the March 2004 workshop, the JDRF Web site highlighted four main speakers from the event, but not Faustman's work. The highlighted speakers were Melton; Mark Keating, a heart researcher affiliated with Harvard and the Hughes Institute, and a co-founder of Hydra Bio, a company seeking to develop drugs that can accelerate regeneration in the heart, pancreas, and other organs; Peter Butler of the University of Southern California; and Lawrence Rosenberg of McGill University in Canada. Rosenberg is a science adviser to GMP Cos., which licensed his "INGAP" technologies for diabetes. The technology is now undergoing a clinical trial funded by pharmaceutical giant Procter & Gamble. Rosenberg also co-founded the company Amaranth Bio, which competes with Faustman's Keel Pharmaceuticals.

"It is impossible to involve good scientists who are not involved in consulting or on the boards of companies," said Insel. None of these speakers' business affiliations were revealed in the JDRF Web site's story on the March workshop. Throughout the Web site, there are only a few references to any of the scientists' or board members' business ties.

In an e-mail to *National Journal*, Cleary said that Web-posting of information about scientists' multiple roles "would require perhaps tens of thousands of pages to post and maintain, ... a small army of administrative staff to manage and update; [would] raise significant disclosure and privacy issues; ... and most importantly, in my opinion, [would] be of little use or value to the general public."

The way information is presented on the Web site is important, because many lay members defer to the JDRF for information. "We get a lot from their Web site and their [e-mailed] research update," said Pamela Anderson of West Jordan, Utah, the mother of a diabetic child, Cody. Since 2002, Sen. Orrin Hatch, R-Utah, has repeatedly cited his meeting with Cody Anderson as a reason he decided to support federal funding of embryo-stem-cell research and to allow human cloning, although not the birth of human clones.

Another lay member of JDRF, Carl Kallsen, who is a grandparent of two children with diabetes in Fort Wayne, Ind., said that "the arguments that I got [from JDRF] primarily were that embryonic was the way to go." Earlier this year, Kallsen

escorted one of his grandchildren to Congress on a lobbying trip arranged by JDRF officials, for which the "platform was that adult stem cells had not made any progress, but embryonic had," Kallsen said.

Because they are desperate for a cure, and because they must work hard to win donations from friends and strangers, JDRF members find it difficult to question or reject the official JDRF position, says former JDRF Chairman Munro. "You're vested, you're so emotionally involved, that you want to believe," he said.

#### PUSHBACK

Faustman's work was highlighted in *The New York Times* in 2001 and again last November, but otherwise has received modest media coverage. That could change, because Faustman's principal backer, the Iacocca Foundation, is publicizing a campaign to raise \$11 million for her pending clinical trial. Raff, head of the Autoimmune Disease Research Foundation, is also raising money. "I received a check today for \$10,000 that was originally made out to JDRF.... The 'J' was changed [by the donor] to 'A' in ADRF," Raff said in an interview.

Other diabetes parents are getting involved. Susan Root and Jacqueline Fusco, two parents of diabetic children, worked with other families last year to raise \$120,000 for Faustman's clinical trial after meeting Faustman. The two scientifically trained women use the Internet extensively to research the claims of advocates and researchers and to argue that Faustman's therapy is the only recorded success among 180 research papers that show some improvement in diabetic or near-diabetic mice.

Some modest political pressure is developing, too. In July, Sen. Sam Brownback, R-Kan., a leading advocate for adult-cell therapies, held a hearing to discuss the therapeutic successes of adult stem cells. At the hearing, Brownback quizzed Robert Goldstein, the JDRF's chief scientific officer, about Faustman's work. Her work is "terrific," Goldstein replied. "It is proof of something in animals

that needs to be translated to people. We hope it works." In October, Van Etten said that Goldstein was referring to regeneration research in general, rather than to Faustman's work in particular.

The debate is sure to continue, regardless of whether Faustman's work is a dead end, because there will be a continuous stream of researchers, coalitions, and groups seeking a share of the JDRF's funds. The JDRF can't hope to progress in a straight line, partly because human biology is exceedingly complex, but also because the lay members find themselves buffeted by claims and counterclaims, supplicants and rivals, pressures and inducements, sore-loser criticism, and ingratiating praise.

That leaves JDRF's lay members—many of them parents whose children are diabetic—heavily dependent on their scientific guides. "We can only trust the information we're given," said board member Smith. ■

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RICHARD INSEL:

"It's impossible to involve good scientists who are not involved in consulting or on the boards of companies."

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